

Patient Issues Committee

June 24, 2002, 9-11am

Howard County General Hospital, Wellness Center

MINUTES

⇒ Introductions and Committee Membership (Diana Ulman)

• Committee members were asked to introduce themselves by name comment on their motivation for participating on this committee.

⇒ Background on Comprehensive Cancer Control (Robert Villanueva/Kate Shockley)

- In September of 2001, the Center for Disease Control and Prevention (CDC) awarded a 2-year cooperative agreement to the Maryland Department of Health & Mental Hygiene to update the 1996 Maryland Cancer Plan.
- Currently there are 13 states funded to implement their Comprehensive Cancer Control plans. In addition, there are 7 states funded under the Planning phase and scheduled to update or rewrite their cancer plans.
- The Maryland Council on Cancer Control and key administrators within the DHMH/ Center for Cancer Surveillance and Control are charged with the oversight for this grant. An organizational chart for the planning process is included among the committee materials.
- One requirement of the grant is that an evaluation component must be incorporated into the planning process. At the end of each meeting, committee members will be asked to complete a one-page evaluation and turn it in to the staff liaison attending your session. The comments will be compiled and shared with you at the beginning of each subsequent meeting. Changes will be made in the meeting process as may be warranted based on the group comments.
- Maryland developed cancer plans in 1991 and 1996, focusing primarily on breast and cervical cancer and tobacco use prevention. The 1996 plan added chapters on prostate and colorectal cancer. Neither of the existing plans included sections dealing with patient issues or quality of life.
- A series of Town Hall Meetings will be conducted this summer as part of the effort to incorporate public input into the cancer plan. A flyer announcing the meetings will be distributed to the committee via email.
- Questions regarding the focus of and publicity for the Town Hall Meetings.

⇒ Committee Operations (Diana Ulman)

- This committee will act as a working group focusing on statewide cancer issues. Brainstorming and open discussion are encouraged. Committee members may need to take on responsibility for compiling resources or doing research to bring back to the committee.
- The next meeting dates of this committee will be July 15 and August 5. Several committee members offered meeting space, but most were willing to return to HCGH. Room reservations will be made and announced via email.
- Pain Management, End of Life Issues, and Diet/Physical Activity are all topics being addressed by separate committees. While there may be some overlap, the Patient Issues committee should try to focus on topics not being addressed by other committees.

⇒ Discussion of Key Issues (Group)

- Cancer survivorship has greatly increased in recent years, and attention should be paid to long-term survivorship (issues that cancer survivors may deal with 10 or 15 years after treatment).
- Discussion of adult survivorship vs. child survivorship
- Member suggestion to encourage research on long-term survivorship, possibly a clinic to follow up with patients on a long-term basis after receiving cancer treatment
- Member suggestion to refer to "equal access" instead of just "access"

- Discussion about why people are not taking advantage of existing programs
- Discussion about insurers and the large amount of control they have over the decisions patients must make regarding their cancer care
- Questions about whether this chapter should include a discussion of access to cancer services before diagnosis such as screening
- Member suggestion that in an ideal world, each cancer patient would be assigned an advocate at the time of diagnosis to walk them through the process and provide all resources necessary
- Discussion of the GBMC Navigator program
- Member suggestion to investigate the idea of a state-sponsored, all-encompassing resource booklet for patients upon diagnosis; also, to have centralized oversight of the information dissemination process so that all patients get appropriate and timely information
- Request for all committee members to bring existing publications and resources to the next meeting, especially those that cover local communities
- Member suggestion to have this committee coordinate the involvement of other state agencies in the cancer planning process (specifically regarding employment issues)
- Member suggestion to hear presentations from committee members regarding existing programs/processes within several Maryland hospitals at the next meeting; also, to have a presentation regarding current research being done at Johns Hopkins from committee member Juliet Cain
- Concerns and discussion about cancer patients who have another type of cancer not being addressed by a sub-committee for the cancer plan; less common types of cancer have not been included in past cancer plans because often, there is no public health intervention to reduce the incidence or mortality from these types of cancer; however, these less common types of cancer can be addressed as part of the Patient Issues section of the new plan because there are relevant public health issues for all cancers once diagnosed
- Member suggestion to involve the Statewide Health Network in the planning process so that efforts are not duplicated
- Member suggestion for all cancer patients to receive info from the state upon diagnosis; this presents problems with patient confidentiality

****For the next meeting, please bring existing resources and come prepared to discuss ideas that have/have not worked in your experience. We hope to prioritize the list of points for discussion so that we can start to focus on the most important issues.**